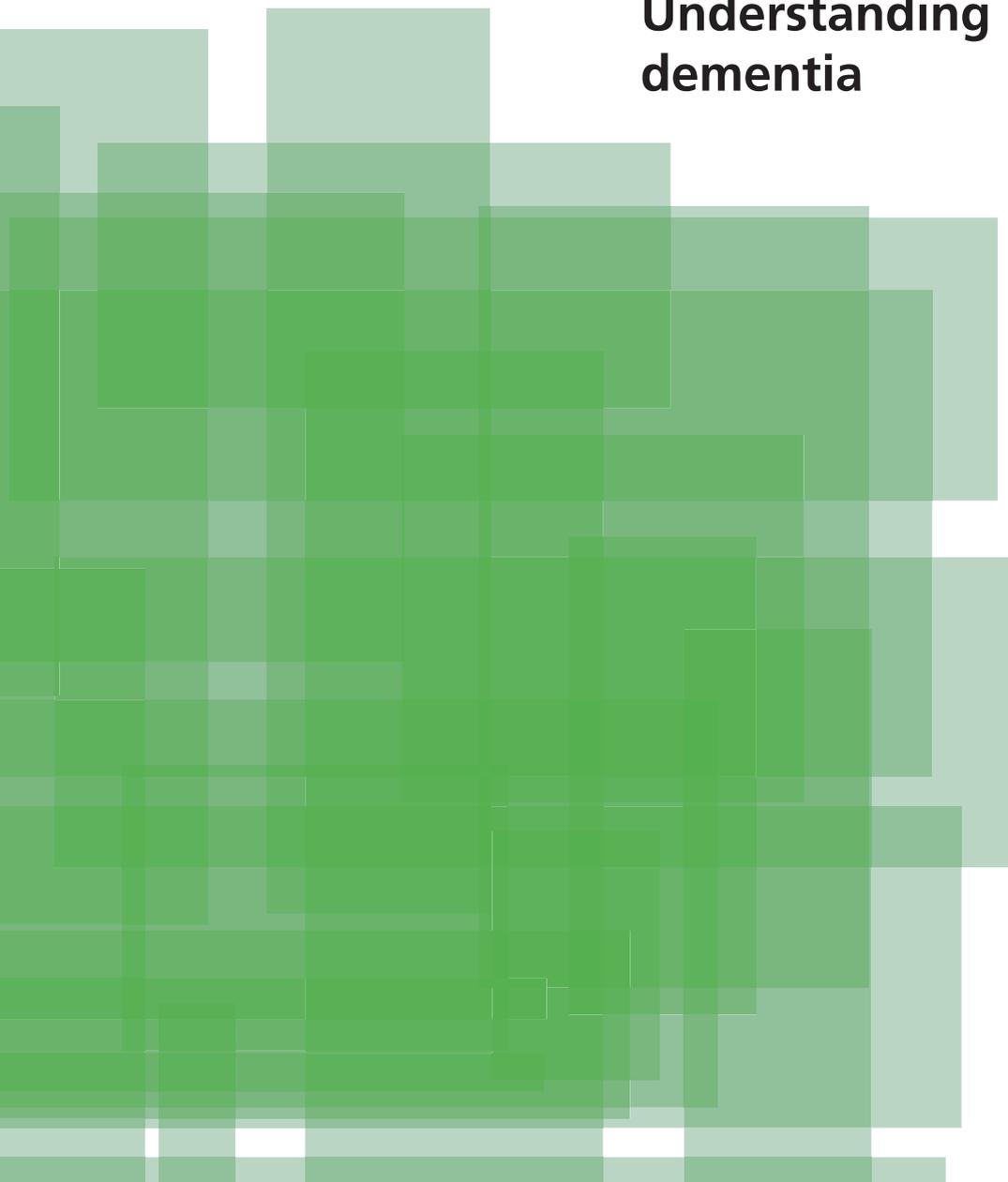




For better  
mental health

# Understanding dementia



*'I first realised something was wrong when she started to ring me at work 10 or 11 times in a single afternoon. Also, around that time, she would get up in the middle of the night and announce it was time to go shopping.'*

*'What worries me most is his smoking. His clothes are peppered with holes, and he's already started a fire at the local hospital by throwing a lighted match into a waste paper bin.'*

*'It's such a shock when your own wife fails to recognise you. "Where's John?", she used to say. "Here I am!", I would answer. "Not you, the other one," she would reply. It breaks your heart.'*

*'It's put Mum under so much stress. It's like having another child to look after. Sometimes, though, you have to laugh. I mean Gran really believes I want to steal her underwear.'*

*'My mother died from a hereditary form of dementia, so yes, I'm at risk. It's a daily anxiety, a daily worry. Most days go by fine, then you drop something, or hesitate over a word, and all the fears come tumbling back.'*

**A diagnosis of dementia can be a devastating blow to an individual, their friends and family. This booklet looks at some of the possible causes, and tells you what can and can't be done to alleviate the condition. It also explains where you can get further advice and information, and how to access help.**



## **What is dementia?**

Dementia is the name for a group of diseases that affect the normal working of the brain. Although the causes are largely unknown, the effects are all too familiar. The changes in the brain slowly lead to memory loss and confusion, and affect people's personality and behaviour. They begin to lose the ability to carry out normal, everyday activities for themselves.

People often think that dementia is an inevitable part of ageing. It is true that conditions resulting from dementia are one of the major causes of death, but only one in five people over 80 develops it. The problem isn't limited to the elderly. In some forms, it can affect people as young as 20. The Alzheimer's Society estimates that over 700,000 people in the UK have dementia, and that 18,500 of them are under 65.

## **How can it be diagnosed?**

Because it's not possible to examine the brain for signs of dementia, a doctor will make a clinical judgement on the basis of various tests. A thorough assessment is vital because there are a number of treatable conditions with dementia-like symptoms that need to be eliminated. Head injuries, brain tumours, certain infections and drugs, alcohol abuse, and thyroid or vitamin deficiencies can all be responsible for similar symptoms. Someone who has been bereaved, become depressed or suffered a psychological trauma may also show his or her distress in this way.

It's been suggested that doctors are too ready to diagnose dementia, and that it has become a handy 'dustbin' term, particularly applied to the elderly. Signs of agitation, sleeplessness, forgetfulness and loss of appetite can easily indicate depression. If someone is labelled with dementia instead, it denies them effective treatment and help. A GP should refer anyone showing signs of confusion to a psychogeriatrician (a specialist in the mental health of elderly people), a psychiatrist or to another medical specialist, for a full assessment.

## **What can cause dementia?**

### **Alzheimer's disease**

This is the most common cause of dementia and affects up to ten per cent of the population aged over 65. It can also occur, much more rarely, in people as young as 35, when there's often a family history of the illness. In most instances, however, it doesn't seem to be an inherited disorder.



Alzheimer's comes on gradually to begin with. The first noticeable sign is usually short-term memory problems – forgetting something that's happened very recently, such as having eaten a few minutes earlier. Scientists have recently proved that head injuries may also contribute to the development of Alzheimer's disease. Doctors have advised those who might be at risk to avoid contact sports and to be rigorous about wearing seat-belts.

### **Vascular dementia (multi-infarct dementia)**

This is the second most common form of dementia and is triggered by a series of small strokes that destroy brain cells. It usually has less effect on the personality than Alzheimer's, and those who have this problem are generally more aware of their limitations. Vascular dementia may come on gradually or quite suddenly. There's usually a settled period, or even an improvement, after each episode of decline. People may experience acute confusion, depression and epileptic fits.

### **Parkinson's disease**

Parkinson's is one of the most common neurological diseases in the UK, and people usually experience dementia in its final stages. The drugs frequently prescribed to relieve the awkward movements that characterise Parkinson's can also cause acute confusional states. It's therefore important to distinguish this from the onset of dementia caused by the illness itself.

### **Huntington's disease**

This is caused by a faulty gene and can develop when people are between 30 and 50. The child of a person with Huntington's disease has a 50 per cent chance of developing the same problem. However, the likelihood decreases with age. Early signs are often twitching muscles in the limbs or face, which worsen as the disease progresses. Drugs may help reduce the awkward movements.

The illness may cause depression, schizophrenia-like states, personality changes and, usually, dementia. Family members can now be tested to see if they will develop the disease (see opposite).

## **Fronto-temporal dementia and Pick's disease**

This covers a range of conditions, including Pick's disease, frontal lobe degeneration and dementia associated with motor neurone disease. They are caused by damage to the frontal lobe or the temporal parts of the brain. This affects behaviour, emotional responses and language skills. The problem tends to appear when people are aged between 50 and 60. The cause is unknown, although in some families there seems to be a hereditary factor.

## **Dementia with Lewy bodies (DLB)**

It's now known that many cases of dementia are caused by Lewy bodies, which are made from an abnormal build up of the protein ubiquitin in the brain. Symptoms can resemble Alzheimer's or Parkinson's, depending on which part of the brain is affected.

## **Down's syndrome and Alzheimer's disease**

For people with Down's syndrome, there is a risk of developing Alzheimer's disease, usually at around the age of 40. This kind of 'early onset' dementia is an inherited problem.

## **Aids-related dementia**

A minority of people with Aids go on to develop a form of dementia in the final stages of the illness.

## **Creutzfeldt Jacob disease (CJD)**

CJD is a very rare type of 'transmissible' dementia caused by prions or proteins that have become abnormal and attack the brain, killing cells. In its old form, it usually affects those over 55. Variant CJD, the new form of the disease linked to the cattle disease BSE, tends to affect much younger people. Early symptoms include memory problems, lack of coordination and mood changes. The disease progresses to shakiness and dementia.

## **Testing for dementia**

There are tests for rare forms of dementia available to those who have a family history of similar problems. Talk to your GP about the implications of being tested, if you think this might apply to you. Those facing this painful choice are always offered counselling.

## What happens when someone has dementia?

There's an enormous variation in how this illness affects people, depending on the type of dementia and the individuals themselves. However, there are usually three distinct stages.

In its early stages, people often appear confused, and forget about things that have just happened. They may not remember where they are, or what they did five minutes ago, but their long-term memory is usually not much affected.

Understandably, people with dementia often dwell on the past. Concentration and decision-making become difficult, and mood changes are frequent. A previously happy person may become irritable or depressed over trifles, and friends and relatives may notice changes, without understanding why. This is extremely frightening and disturbing. We all experience memory lapses from time to time, and have difficulty putting names to faces, but someone with dementia experiences this to a much greater extent. It's not hard to imagine how frightening this must be.

The second stage, known as moderate dementia, brings more obvious confusion, forgetfulness and mood changes. The person may become anxious and aggressive. They may wander restlessly around the house and be up and about at night. They may try to search the streets for a place or person from the past. They may also become suspicious of loved ones. (See Mind's booklet *Understanding paranoia*, details under *Further reading*, on p. 14.) Personal safety can be an issue, especially for those who smoke or cook. Even simple things like dressing may become difficult. The pressure upon carers is enormous, as it becomes increasingly difficult to leave someone with dementia on their own.

In the final stages of the illness, a great deal of help is needed. Long-term memory may still be strong, but often people are unable to recognise even close family and friends. People stop being able to talk properly or to understand what is said to them. Incontinence is common. During the later stages, most people become increasingly frail and may be confined to a wheelchair and then to bed. This makes them especially vulnerable to infections such as pneumonia, which can be fatal.



## What treatments are there?

Unfortunately, there is no cure for dementia as yet, but there are drugs available to provide some relief, and many other strategies for coping. Specialist services, such as neurologists, consultants in old age psychiatry and memory clinics can help. Ask your GP about these. (See, also, *Further reading*, on p. 14.)

Tranquillisers, antidepressants and anxiety-relieving drugs can be used to relieve symptoms, such as irritability, anxiety, restlessness and depression, but they may have side effects (see *Further reading*, on p. 14).

The drugs Aricept (donepezil hydrochloride), Exelon (rivastigmine) and Reminyl (also called galantamine) may help control the symptoms of Alzheimer's disease, for a limited period of time, in people who have mild to moderate forms. They work by maintaining levels of the chemical acetylcholine, which affects nerve cell communication and memory. Side effects may include diarrhoea, nausea, insomnia, fatigue and loss of appetite, but the drugs may improve cognitive functioning. Not all health authorities fund them. A new drug, Ebixa (memantine hydrochloride), may protect cells from calcium damage and temporarily slow symptoms, or even the disease itself, in later stages of Alzheimer's. But, it is not always effective, and fewer people benefit as time passes. Research is ongoing.

Much can be done for people's psychological health without relying on drugs, by making them feel safe and cared for, and by keeping distress to a minimum (see below). Good nutrition is vital, and extra vitamins C, B12 and E may be important.

### Complementary therapies

Acupuncture, aromatherapy, art and drama therapy, herbal remedies, massage and music therapy are among the complementary remedies that people say they have found helpful in dealing with Alzheimer's disease. Art therapy, for example, may improve coordination, concentration and general wellbeing, while aromatherapy and massage can help reduce anxiety and tension.

Some herbal remedies, such as ginkgo biloba (currently under clinical trial), are reputed to help improve memory. (For more information, consult the *Useful organisations*, on p. 12, and *How to cope with memory loss*, details on p. 14.) It's important to recognise, when taking any form of remedy, that it may have side effects of its own, or react with other medicines. Always tell your doctor, pharmacist or complementary practitioner what other treatments you are having.



### **Why is early diagnosis a good idea?**

Sometimes, GPs don't recognise the early symptoms of dementia, mistaking them for normal signs of old age. Or they may feel that giving someone such a diagnosis is pointless. But although the changes to the brain can't be stopped or reversed, an early diagnosis can make a big difference to people's future, by allowing access to treatments.

Early diagnosis allows people to make the necessary adjustments and to plan ahead, together with their families. They can sort out their financial affairs and participate in decisions about their future, including making an advance directive (a living will) that outlines their wishes about future treatment. It also gives them time to establish routines and strategies that will help them maintain independence. (See *How to cope with memory loss*, details on p. 14.)

Understandably, when someone first hears their diagnosis, the reaction is likely to be shock, anger, depression and fear. However, recent research has revealed that people still prefer to be told, provided this is done in a sensitive manner, and that they are offered the opportunity to talk about it and receive plenty of subsequent support. A GP may be able to refer the person to a counsellor or psychotherapist to help them deal with the feelings that arise. It may also be possible to join a local support group of people with similar problems. (See *Useful organisations*, on p. 12.)

## Sorting out financial and legal matters

Anyone with dementia will gradually become unable to manage his or her own affairs. Informal arrangements often exist to get around this problem, with a friend or relative collecting benefits and pensions, for instance. It's a good idea, however, to get legal advice before any major problems arise. For example, if spouses own their home jointly, there could be problems if the partner who does not have dementia wants to sell it, or use the proceeds of the sale.

In the early stages of the disease, the person with dementia may be well enough to give someone the legal power to manage their affairs (Power of Attorney). A solicitor can arrange this. However, if the person's mental capacity is too limited for this, it may be necessary to put his or her affairs under the jurisdiction of the Court of Protection. To find out more about this, contact The Public Guardianship Office. (See *Useful organisations*, on p. 12.) Mind has produced a booklet, *Mind rights guide 7: managing your finances* (see p. 14). You can also get advice on these matters from a citizens advice bureau (CAB), a law centre, Mind's Legal Unit, the Alzheimer's Society or from any solicitor.

## What help will people who have dementia need?

During the early stages, a person may cope quite well in familiar surroundings, but may be confused when they are somewhere they don't know. It's a good idea to help people to lead as normal a life as possible, in their own homes, for as long as they can.

- Develop and keep to daily routines. This is the most effective means of maintaining independence.
- Make sure the environment is as safe as possible. Because the dementia affects physical coordination, it's important to check floors for loose rugs or trailing wires. Fit smoke alarms, keep matches hidden and switch off the gas at the mains, if the person is left on their own.
- Reinforce links with reality by having plenty of clocks and calendars to remind him or her of the day and time.



- If the person can't be in their own home, it's a good idea to surround them with familiar objects as far possible, such as a favourite chair or picture.
- Play to the person's strengths, not their weaknesses, by focusing on what they can do. Modify activities to allow as much opportunity as possible for positive and engaging experiences.
- Take advantage of their good long-term memory. Old photograph albums or music can help to reduce anxiety by bringing happier times to mind.
- Remember that people with dementia still have some understanding and some accurate memories. Tender, loving kindness is what they need.

Get as much outside help as possible. Everybody in touch with mental health services is entitled to an assessment under the Care Programme Approach (CPA). This should give them access to services, such as meals-on-wheels, or a home help, which can help them maintain independence, dignity and privacy for much longer. An occupational therapist can make life much easier by arranging for bath equipment and banister rails to be installed, and for a wheelchair and special raised seating to be provided. Other medical professionals who could be involved include physiotherapists, language therapists and community psychiatric nurses (CPNs).

Although physical treatment is limited, a lot can be done for the emotional health of those with dementia. People who have dementia live very much in a world of their own, which observers can only hear, see and try to understand at second hand. Some therapists believe that because of this, we fail to see that what appears to be absurd and irrational behaviour can have a meaning. A lot can be learnt from body language and facial expression. For example, an elderly woman shaking her fists in the air may be reliving an argument with her husband that was never resolved. Rather than just dismissing the behaviour, it could be worthwhile acknowledging the fear hidden within it, and trying to allay it.

As the illness progresses and dependency increases, it may become very difficult for the person to manage at home or with relatives. A care home or nursing home may be the only option. This is a decision that has to be made for the person by their relatives or by a social worker. It's always a difficult decision, a balancing of needs and safety risks. What may look like a squalid and degrading environment to an outsider, may amount to freedom for the person with dementia.

## **What about the needs of the carer?**

It's extremely upsetting and exhausting when someone you are close to develops dementia. They may say hurtful things to the people who care about them most. It may feel as though you are losing the person you love, and living with a stranger.

Most people with dementia are in the care of relatives, but levels of help in the community can be woefully inadequate. This often increases carers' feelings of frustration, isolation and helplessness, and many believe that inadequate community care creates as many difficulties as the dementia itself. The strain on family and friends is enormous, as dementia forces them to make agonising choices. They need all the emotional and practical support they can get.

## **Getting the help you need**

As the disease progresses, find out about local day centres, and the chances of a holiday relief or a respite care bed in your local hospital. Ask the GP or the responsible care coordinator from social services. Be prepared to press for your rights to the services you need. If the person you care for is assessed under the Care Programme Approach, you are entitled to have your needs assessed, too.

- Don't wait until you're desperate before asking for help.
- Make sure you know about benefits – your local CAB or care coordinator will be able to advise you.



- Consider joining a local self-help group to meet others in a similar situation. As well as being able to share frustrations and unload feelings, these groups provide an invaluable source of practical information. (See *Useful organisations*, below.)
- Remember that guilt, anger, frustration and grief are common responses among carers. The fact that there is no cure for dementia can make carers feel very helpless.
- Try not to lose touch with your own friends and interests.

Although institutional care sometimes has a poor reputation, not all homes are the same. It's likely that, in the end, the person you are caring for will require this kind of help. Be prepared to accept that the time may come when you can no longer cope, and admission to hospital or residential care is necessary.

Many people feel guilty about handing over to someone else. But those who have been through the process stress that, although the practical caring may have come to an end, the emotional caring continues. On a more positive note, many have also said that, once relieved of a draining, 24-hour responsibility, they were able to recover a relationship that had become soured by stress.

It can be extremely difficult to care for someone with dementia. You may feel you would benefit from the opportunity to talk to someone. Your GP may be able to arrange for you to see a counsellor or psychotherapist, or there may be local organisations offering low-cost schemes. (See *Useful organisations*, below.)



## **Useful organisations**

### **Mind**

Mind is the leading mental health organisation in England and Wales, providing a unique range of services through its local associations, to enable people with experience of mental distress to have a better quality of life. For more information about any mental health issues, including details of your nearest local Mind association, contact the Mind website: [www.mind.org.uk](http://www.mind.org.uk) or Mind<sup>in</sup>foline on 0845 766 0163.

## **Age Concern England**

Astral House, 1268 London Road, London SW16 4ER  
information line: 0800 009 966, web: [www.ageconcern.org.uk](http://www.ageconcern.org.uk)

## **Alzheimer's Society**

Gordon House, 10 Greencoat Place, London SW1P 1PH  
helpline: 0845 300 0336, tel. 020 7306 0606  
web: [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

## **Carers UK**

20–25 Glasshouse Yard, London EC1A 4JT  
helpline: 0808 808 7777, web: [www.carersonline.org.uk](http://www.carersonline.org.uk)

## **CJD Support Network**

Birchwood, Heath Top, Ashley Heath, Market Drayton  
Shropshire TF9 4QR  
helpline: 01630 673 973, web: [www.cjdsupport.net](http://www.cjdsupport.net)

## **Huntington's Disease Association**

108 Battersea High Street, London SW11 3HP  
tel. 020 7223 7000, web: [www.hda.org.uk](http://www.hda.org.uk)

## **National Prion Clinic**

Department of Neurology, St Mary's Hospital, Praed Street,  
London W2 1NY  
tel. 020 7886 6883, web: [www.st-marys.nhs.uk/services/p6.htm](http://www.st-marys.nhs.uk/services/p6.htm)

## **Parkinson's Disease Society**

215 Vauxhall Bridge Road, London SW1V 1EJ  
helpline: 0808 800 0303, web: [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

## **Public Guardianship Office**

Archway Tower, 2 Junction Road, London N19 5SZ  
helpline: 020 7664 7300 or 0845 330 2900  
web: [www.guardianship.gov.uk](http://www.guardianship.gov.uk)

## **The Stroke Association**

Stroke House, 240 City Road, London EC1V 2PR  
helpline: 0845 303 3100, web: [www.stroke.org.uk](http://www.stroke.org.uk)

## Further reading

- Anxiety and tension: symptoms, causes, orthodox treatment and how herbal medicine will help* J. Wright (How To Books 2002) £6.99
- The BMA family doctor guide to stress* (Dorling Kindersley 1999) £4.99
- Coping with anxiety and depression* S. Trickett (Sheldon Press 1997) £6.99
- The food and mood handbook* A. Geary (Thorsons 2001) £12.99
- The forgetting – understanding Alzheimer's: a biography of a disease* D. Shenk (Flamingo 2002) £8.99
- Good mood food* M. Van Straten (Cassell 2002) £10.99
- Healing minds* J. Wallcraft (Mental Health Foundation 1998) £12
- How to cope as a carer* (Mind 2003) £1
- How to cope with memory loss* (Mind 2004) £1
- How to cope with sleep problems* (Mind 2003) £1
- How to look after yourself* (Mind 2002) £1
- Making sense of antidepressants* (Mind 2004) £3.50
- Making sense of antipsychotics (major tranquillisers)* (Mind 2003) £3.50
- Making sense of cognitive behaviour therapy* (Mind 2001) £3.50
- Making sense of herbal remedies* (Mind 2000) £3.50
- Making sense of homeopathy* (Mind 2001) £3.50
- Making sense of sleeping pills* (Mind 2000) £3.50
- Making sense of traditional Chinese medicine* (Mind 2001) £3.50
- Mental Health Act 1983: an outline guide* (Mind 2003) £1
- Mental illness: a handbook for carers* (JKP 2001) £15.95
- The Mind guide to food and mood* (Mind 2000) £1
- The Mind guide to managing stress* (Mind 2003) £1
- The Mind guide to massage* (Mind 2004) £1
- The Mind guide to physical activity* (Mind 2001) £1
- The Mind guide to relaxation* (Mind 2004) £1
- Understanding anxiety* (Mind 2003) £1
- Understanding depression* (Mind 2004) £1
- Understanding mental illness* (Mind 2004) £1
- Understanding talking treatments* (Mind 2002) £1

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Scottish Association for Mental Health tel. 0141 568 7000

Northern Ireland Association for Mental Health tel. 028 9032 8474

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